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# Stigmatization caused by hair loss – a systematic literature review

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## Summary

Hair loss is a symptom that can cause stigmatization and severe impairment of quality of life. The aim of this systematic review was to evaluate the literature on stigmatization of hair loss. Using predefined MeSH terms and keywords, a systematic search was performed in the databases MEDLINE (PubMed), EMBASE, PsycINFO and PsycNET. No time restriction was chosen (last update: May 07, 2019; PROSPERO registration number: CRD42019122966). A total of 98 studies were identified, of which eleven were selected for inclusion in this work. The Hairdex, a questionnaire on disease-specific quality of life, was the most frequently used instrument for the quantitative assessment of stigma. The studies were highly heterogeneous and values for stigmatization of androgenetic alopecia varied widely. However, regardless of the pathogenesis, patients with hair loss often suffer from stigmatization which limits their quality of life. Stigmatization of people with visible skin lesions has often been neglected in clinical practice and in daily contact with affected individuals. Studies that specifically address the stigma of hair loss are rare. Further studies are needed to achieve comparability within pathogeneses as well as with other visible dermatoses in order to better understand the enormous psychosocial burden of hair loss.

## Background

Hair loss is, irrespective of its pathogenesis or severity, a cause of distress for affected individuals that is often underestimated by outside parties [1–3]. Pathogeneses vary and include androgenetic alopecia, alopecia areata, diffuse alopecia, and therapy-induced hair loss [4, 5]. While modern therapies are on the advance [6–8], affected individuals often suffer from internalized and external stigmatization in addition to a reduced quality of life and a large number of psychological comorbidities due to their changed appearance [4, 9]. Stigmatization describes a phenomenon that excludes affected individuals from complete social acceptance. This phenomenon may be triggered by the patients themselves (internalized stigma), or it may be induced by their environment (external stigma) [10]. Given the heavy burden on affected individuals, stigmatization may then result in psychological diseases [4] and severely impair the quality of life [11]. Dermatological disorders are common [12], and because of stigmatization in case of visible skin changes and its impact on the life of many affected individuals, the German Federal Ministry of Health (BMG) initiated

the project initiative “*In meiner Haut*” (in my skin) for the destigmatization of people with visible skin alterations [13]. In this context, an expert panel consisting of patient representatives, scientists and physicians currently develops and scientifically evaluates various formats of intervention in order to reduce stigmatization due to visible skin diseases. For an evidence-based approach, it is essential to obtain an overview of the existing literature to determine the need and plan for interventions, where necessary. Accordingly, it is the aim of this systematic review to compile a structured summary of the literature on internalized and external stigmatization due to hair loss.

## Material and Methods

This systematic review was conducted according to the guidelines of *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) [14] and *Meta-Analysis of Observational Studies in Epidemiology* (MOOSE) [15]. Prior to execution, the underlying protocol was registered in the PROSPERO database for systematic reviews (registration number: CRD42019122966) [16].

Search strategy and selection process

The databases MEDLINE (PubMed), EMBASE, PsycINFO, and PsycNET were searched systematically by means of predefined search terms consisting of *Medical Subject Headings (MeSH-terms)* terms and other selected keywords. The following search terms were used: “alopecia”, “stigma”, and “humans”, as well as corresponding alternative terms (Table 1). In addition, the source references of the full publications in the last stage of the selection process were manually searched for additional suitable publications. No time restriction was chosen (last update: May 07, 2019).

All identified articles were assessed by two independent reviewers (MS and LT; both MPH and PhD students). In phase I of the selection process, titles and abstracts were read and evaluated based on predefined criteria. In phase II, the full texts of those studies assessed as relevant during phase I were evaluated and reviewed with respect to inclusion and exclusion criteria (Figure 1). Discrepancies were discussed and, in case of disagreement, a consensus was reached in consultation with a third reviewer (AZ; PD Dr. Dr. med., MPH; senior physician). If the full text was not available, the corresponding author was contacted by e-mail.

Table 1 Conception of the used search term according to respective guidelines.

Core concepts	Concept 1	Concept 2	Concept 3	Concept 4
	Participants	Exposure	Outcome	Language
Keywords and MeSH terms used for search	<ul style="list-style-type: none"> <li>– Adolescent</li> <li>– Adult</li> <li>– Aged</li> <li>– Child</li> <li>– Female</li> <li>– Humans</li> <li>– Male</li> <li>– Middle Aged</li> <li>– Young Adult</li> </ul>	<ul style="list-style-type: none"> <li>– Alopecia</li> <li>– Alopecia Areata</li> <li>– Alopecia Areata totalis</li> <li>– Alopecia Areata universalis</li> <li>– Alopecia Areata/epidemiology</li> <li>– Alopecia Areata/mental health*</li> <li>– Alopecia Areata/psychology*</li> <li>– Alopecia Areata/therapy*</li> <li>– Alopecia areolaris syphilitica</li> <li>– Alopecia/chemically induced*</li> <li>– Alopecia/psychology*</li> <li>– Alopecia/rehabilitation*</li> <li>– Androgenetic Alopecia</li> <li>– Bald Head</li> <li>– Bald</li> <li>– Effluvium</li> <li>– Frontal fibrosing alopecia</li> <li>– Hair Loss</li> <li>– Ophiasis</li> <li>– Postmenopausal frontal fibrosing alopecia</li> <li>– Telogen effluvium</li> <li>– Trichotillomania</li> </ul>	<ul style="list-style-type: none"> <li>– Internalised Stigma</li> <li>– Internalized Stigma</li> <li>– Perceived stigma</li> <li>– Self-Stigma</li> <li>– Social Stigma*</li> <li>– Stereotyping</li> <li>– Stigma</li> <li>– Stigma, social</li> <li>– Stigmata</li> <li>– Stigmatising</li> <li>– Stigmatisation</li> <li>– Stigmatization</li> <li>– Stigmatize</li> </ul>	<ul style="list-style-type: none"> <li>– English</li> <li>– German</li> </ul>
Combined search term	(Adolescent OR Adult OR Aged OR Child OR Female OR Humans OR Male OR Middle Aged OR Young Adult) AND (Internalised Stigma OR Internalized Stigma OR Perceived stigma OR Self-Stigma OR Social Stigma* OR Stereotyping OR Stigma OR Stigma, social OR Stigmata OR Stigmatising OR Stigmatization OR Stigmatisation OR Stigmatize) AND (alopecia OR alopecia areata OR alopecia areata totalis OR alopecia areata universalis OR alopecia areata/epidemiology OR alopecia areata/mental health* OR alopecia areata/ psychology* OR alopecia areata/ therapy* OR alopecia areolar syphilitic OR alopecia/chemically induced* OR alopecia/ psychology* OR alopecia/ rehabilitation* OR androgenetic alopecia OR bald head OR bald OR effluvium OR frontal fibrosing alopecia OR hair loss OR ophiasis postmenopausal frontal fibrosing alopecia OR telogen effluvium OR Trichotillomania) AND ((english [language]) OR (german [language])).			

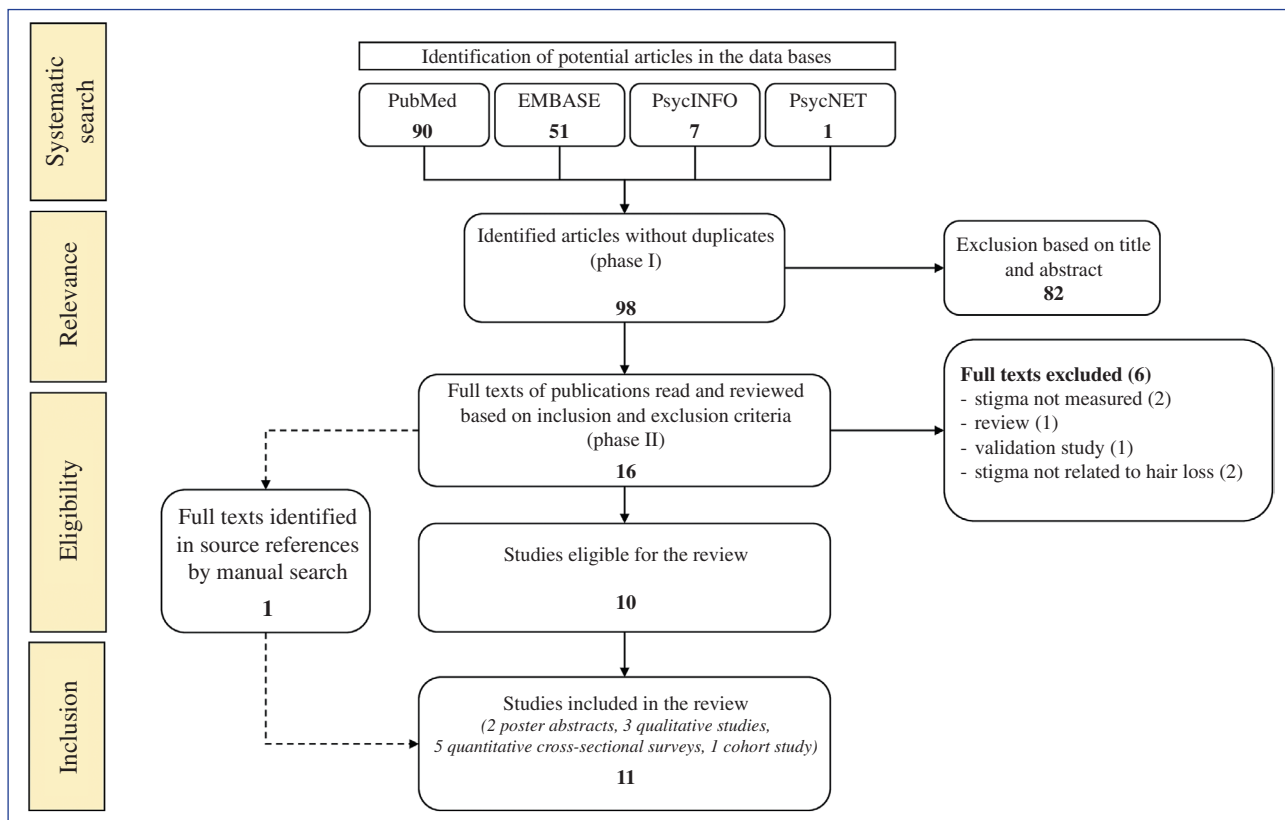


Figure 1 Flowchart with counts of the literature used at any time during the literature search.

### Inclusion criteria

All study designs (quantitative and qualitative studies) were considered for this review. Studies were assessed as relevant during phase I and phase II if they (i) addressed external or internalized stigmatization of individuals with hair loss, or (ii) included health-related stigma due to hair loss as dependent or independent variable.

### Exclusion criteria

Studies were excluded in phase II if they (i) were not available in the English or German language, (ii) consisted of an editorial, comment, or study protocol, (iii) did not present any own data, or (iv) addressed exclusively stigma not attributed to hair loss (for example, stigmatization due to gender, sexuality, or ethnic group).

### Data collection and quality assessment

The data extraction and study assessment described below was performed independently by both MS and LT. Where present, the following data were extracted from each study: title, last name of first author, year of publication, type of article (full publication/abstract), study design, methodology

and instruments of data acquisition, patient number, and collected outcome variables.

All included cross-sectional studies were assessed by two authors (MS, LT) with the checklist *Strengthening the Reporting of Observational Studies in Epidemiology* (STROBE) [17]. Qualitative studies were assessed with the checklist *Consolidated Criteria for Reporting Qualitative Research* (COREQ) [18]. The development version of the STROBE checklist for conference abstracts was used to assess publications only available as abstracts [17].

The quality of a study was assessed based on the proportion of described subitems considered relevant and reported in the corresponding checklist: A (very good) > 80 %, B (good) 80–50 % and C (too inaccurate) < 50 % [19]. In case of discrepancy, the two quality assessments were discussed and, if no consensus was reached, AZ was included in the final decision. The *interrater* reliability between MS and LT was 54.5 %, and any disagreement could be resolved without assistance by AZ. Exclusion due to inferior quality of articles was not predefined.

### Results

The systematic literature search in the four databases identified 98 publications. After exclusion of publications based on titles and abstracts, 16 articles remained for examination of

the full texts. Another study was identified by manual search of the reference lists in the inspected full publications. After evaluation of the full texts, eleven studies were included in this review (Figure 1).

The characteristics of the included studies and their associated authors are described in Table 2. The majority of the articles came from Europe (5/11) and Turkey (3/11) and were predominantly published in dermatological (5/11) and psychological (3/11) journals. The average number of authors

per publication was 5.5, and most first authors were affiliated with a dermatological or psychological institution (36.4 % each). The median impact factor of the included scientific journals was 3.117 with a range from 0.884 to 8.017. The articles were published in ten different journals. Two of the identified articles were published in the *International Journal of Trichology* (Table 2). The included publications comprised two poster abstracts [20, 21], three qualitative studies [22–24], five quantitative cross-sectional surveys [25–29], and

**Table 2** Overview over the characteristics of included articles and authors (n = 11).

General characteristics of the included articles			n (%)
Authors	Number of authors	1–3	3 (27.3)
		4–6	4 (36.4)
		> 6	4 (36.4)
	Countries of institutions of the respective first authors	Europe	5 (45.5)
		Germany	1 (9.1)
		France	1 (9.1)
		Netherlands	1 (9.1)
		Italy	1 (9.1)
		United Kingdom	1 (9.1)
		India	1 (9.1)
		Tunisia	1 (9.1)
		Turkey	3 (27.3)
		USA	1 (9.1)
		Scientific journals	Topics of scientific journals
Psychology	3 (27.3)		
Oncology	2 (18.2)		
Patient-centered medicine	1 (9.1)		
Titles of scientific journals	International Journal of Trichology		2 (18.2)
	Anais Brasileiros De Dermatologia		1 (9.1)
	British Journal of Dermatology		1 (9.1)
	Cancer Nursing		1 (9.1)
	European Journal of Cancer		1 (9.1)
	European Psychiatry		1 (9.1)
	Health Psychology		1 (9.1)
	JAMA Dermatology		1 (9.1)
	Journal of Investigative Dermatology		1 (9.1)
	Patient Education and Counseling		1 (9.1)
Impact factor 2017 (median, range)		3.177 (0.884–8.107)	

one retrospective cohort study, which, however, presented only a cross-sectional report on stigmatization [30]. Subdivided according to the pathogenesis underlying hair loss, five studies focused on therapy-induced hair loss (chemotherapy or endocrine therapy) [20, 22–24, 30], four on androgenetic alopecia [25, 27–29], three on alopecia areata [21, 25, 29], and one on diffuse alopecia [28] (Table 3).

## Measuring instruments

The Hairdex [11] was used in four of the eight quantitative studies and thus the most frequently utilized instrument [25, 27, 28, 30]. It consists of 48 questions, such as “The condition of my hair impairs my societal and social life” or “The condition of my hair makes it more difficult for me to achieve as much as usual”, and is specifically concerned with the impairment of the quality of life due to hair loss. The factor of stigmatization is evaluated with a subscale consisting of eight questions (Cronbach's  $\alpha$  of 0.68 [11]). For each question, affected individuals assess on a five-step Likert scale to what degree statements such as “The condition of my hair is disfiguring me” apply to them. Subsequently, the achieved scores for both total scale and individual subscales are linearly transformed into a value range from 0–100 with higher values indicating more severe impairment.

Only three studies used measuring instruments specifically developed for measuring stigma. Specifically, the *Internalized Stigma Scale* (ISS, Cronbach's  $\alpha$  for psoriasis: 0.65–0.78) [21], the *Feelings of Stigmatization Questionnaire* (Cronbach's  $\alpha$  for alopecia areata: 0.93) [26], and a combination consisting of a modified Stroop test and two approach-avoidance tasks [29] were used. In one poster abstract, the measuring instrument used for the determination of stigmatization was not comprehensible [20]. The categorization of the measuring instruments with respect to assessment of internalized and external stigma is depicted in Table 4.

## Alopecia areata and androgenetic alopecia

A study by Temel et al. [21] showed a significant correlation between stigmatization due to alopecia areata and both the *Dermatology Life Quality Index* (DLQI;  $r = 0.508$ ) and general mental health measured with the *General Health Questionnaire* (GHQ;  $r = 0.329$ ). The scores for internalized stigmatization measured with the ISS [31] were comparable to the scores of patients with acne vulgaris and higher than those of patients with vitiligo (59.5 vs. 59.5 vs. 51.7) [21].

In another study, patients with various forms of hair loss (54 % alopecia universalis, 18 % alopecia totalis, 26 % alopecia areata, 2 % androgenetic alopecia) and their partners were examined by a combination of a modified Stroop test and two approach-avoidance tasks to quantify internalized

and external stigma. The results of this study indicate that patients with hair loss are affected more by internalized stigmatization while patients with psoriasis rather react to stimuli that imply external stigma [29].

A third study compared alopecia areata and androgenetic alopecia [25]. Although, based on the Hairdex, patients with alopecia areata report a lower impairment of their quality of life (57.0 vs. 68.4;  $p = 0.025$ ), no statistically significant difference was found on the stigmatization subscale (4.7 vs. 5.6;  $p = 0.372$ ). Overall, there was a correlation between disease duration of alopecia areata and a higher impairment of the quality of life due to stigmatization ( $r = 0.54$ ;  $p = 0.001$ ). In both groups, women seem to experience more stigmatization, although this finding was not significant [25]. Moreover, when directly compared to patients with psychiatric diseases, such as depression or anxiety disorders, patients with alopecia areata showed a higher degree of stigmatization ( $74.1 \pm 23.5$  vs.  $52.0 \pm 24.3$ ;  $p < 0.01$ ) [26].

According to a study by Sawant et al. [27] that addressed androgenetic alopecia exclusively in men, younger and less severely affected men were less impaired by stigmatization [Hairdex subscale: 13.2 vs. 13.9 and 13.0 vs. 13.9] [27]. Another study on women with diffuse or androgenetic alopecia showed that patients with a highly visible form of diffuse alopecia were more severely affected by stigmatization than those with mild alopecia (37.8 vs. 16). The perceived stigmatization of affected patients increased steadily with increasing severity of androgenetic alopecia (20.1 to 26.9) [28].

## Therapy-induced alopecia

Approximately half of the studies (5/11) addressed hair loss induced either by preceding chemotherapy for various tumors [20, 22–24] or endocrine therapy for breast cancer [30]. The quantitative assessments showed that 30.4 % of the patients considered hair loss as the most distressing side effect and that loss of hair resulted in stigmatization with impaired social interactions in 45.8 % of the patients [20]. Moreover, Freites-Martinez et al. [30] observed a mean Hairdex score of 14.6 ( $\pm 17.0$ ) on the subscale for stigmatization while the score for the total Hairdex was 25.6 ( $\pm 14.5$ ). Quantitative studies indicated psychological stress due to stigmatization, too. For example, patients were cited with statements such as “*I think the worst thing that bothered me was people used to look at me and be sort of “aah.” And then they sort of say, “for the grace of God it's not me”...*” (female patient, 61 years, England) [23]. The experienced stigmatization was also described by statements such as “*Our cultural environment extremely values women's [healthy] looks and it doesn't allow us to show ourselves as we are...*” (female patient, 59 years, Italy) [24]. Affected individuals often try to hide the occurring hair loss [22]. This was often done by

Table 3 Characteristics of included studies.

First author, year of publication, quality*	Reference	Study design	Subjects			Methods and results		
			Number of participants (n)	Type of hair loss	Percentage of female subjects	Mean age in years (range)	Measuring instruments <sup>1</sup>	Relevant results <sup>2</sup>
Baati et al. 2010 B	[20]	Quantitative cross-sectional study, questionnaire-based	24 participants	Chemotherapy-induced alopecia	44.8 %	45.9	<ul style="list-style-type: none"> <li>- <i>Rosenberg's Self-Esteem scale</i></li> <li>- <i>Bruchon-Schweitzer's Body-Image Questionnaire (QIC)</i></li> <li>- <i>Hospital Anxiety and Depression scale (HAD)</i></li> <li>- <i>Brief cope</i></li> </ul>	45.8 % of the affected individuals suffered from stigma due to hair loss impairing their social interactions. 30.4 % of the patients specified alopecia as the most distressing side effect of chemotherapy.
Freites-Martinez et al. 2017 C	[30]	Quantitative longitudinal study, only cross-sectional acquisition of stigmatization, questionnaire-based	112 participants (52 with information about stigmatization)	Alopecia induced by endocrine therapy	100 %	59.8 (34–90)	<ul style="list-style-type: none"> <li>- classification of alopecia according to severity</li> <li>- <i>Folliscope 2.8</i> hair density</li> <li>- <i>Hairdex</i></li> <li>- response to therapy</li> </ul>	The mean score on the <i>Hairdex</i> scale was 25.6 (± 14.5). The score on the stigmatization subscale was 14.6 (± 17.0).
Gonul et al. 2018 B	[25]	Quantitative cross-sectional study, questionnaire-based	138 participants	Alopecia areata (n = 56) Androgenetic alopecia (n = 82)	44.6 % 63.4 %	29.3 30.1	<ul style="list-style-type: none"> <li>- <i>Hairdex</i></li> <li>- a Turkish instrument for quality of life (TLQ)</li> </ul>	No significant difference was found for the stigmatization subscale [4.65 vs. 5.60]. Women seemed to suffer more severely from stigma. Patients suffering from alopecia already for some time reported significantly higher stigmatization.

First author, year of publication, quality*	Reference	Study design	Subjects			Methods and results		
			Number of participants (n)	Type of hair loss	Percentage of female subjects	Mean age in years (range)	Measuring instruments <sup>1</sup>	Relevant results <sup>2</sup>
Kacar et al. 2016 B	[26]	Quantitative cross-sectional study, questionnaire-based	82 participants, 40 with hair loss	Alopecia areata	35.0 %	28.4	– <i>Feelings of Stigmatization Questionnaire</i> by Ginsburg and Link	Patients with alopecia areata seem to be affected more severely by stigmatization than patients with psychiatric diseases.
Rosman 2004 B	[22]	Qualitative study, guideline-based	35 participants	Chemotherapy-induced alopecia	74.3 %	2 groups: 51.5 and 58	– explorative study – disease history – signs of fatigue – the topic of hair loss arose spontaneously	Affected individuals report of hiding and concealing their hair loss to avoid stigma.
Sawant et al. 2010 B	[27]	Quantitative cross-sectional study, questionnaire-based	37 participants	Androgenetic alopecia	0 %	N/A	– lifestyle indices – Hairdex – <i>Symptom Check List-90-R</i> (SCL-90-R) – <i>Stressful Life Events Scale</i>	Young men (15 to 25 years) [13.17 vs. 13.90] and less affected men [12.99 vs. 13.94] seem to be less affected by stigma.
Schmidt et al. 2000 B	[28]	Quantitative cross-sectional study, questionnaire-based	50 participants (44 with information about stigmatization)	Diffuse or androgenetic alopecia	100 %	42.3 (19–66)	– Hairdex – <i>Berne Coping Forms</i> – Short version of <i>Social Support Questionnaire</i>	Increased perception of stigmatization in female patients with highly visible compared to slightly visible diffuse alopecia [37.78 vs. 16.89]. In androgenetic alopecia, the perceived stigmatization is increasing with severity [20.08–26.89].

Continued



Table 3 Continued.

First author, year of publication, quality*	Reference	Study design	Subjects			Methods and results		
			Number of participants (n)	Type of hair loss	Percentage of female subjects	Mean age in years (range)	Measuring instruments <sup>1</sup>	Relevant results <sup>2</sup>
Temel et al. 2017 B	[21]	Quantitative cross-sectional study, questionnaire-based	150 participants, 50 with hair loss	Alopecia areata	N/A	N/A	<ul style="list-style-type: none"> <li>- <i>Internalized Stigma Scale</i> (ISS)</li> <li>- <i>Dermatology Life Quality Index</i> (DLQI)</li> <li>- <i>Perceived Health Status</i> (PHS)</li> <li>- <i>General Health Questionnaire</i> (GHQ)</li> <li>- <i>Acne Quality of Life Scale</i> (AQOL)</li> </ul>	<p>The mean score on the Internalized Stigma Scale (ISS) of patients with alopecia areata was comparable with that of acne vulgaris and higher than that of patients with vitiligo (59.46 vs. 59.48 vs. 51.68). For patients with alopecia, a significant correlation was found between the scores on the ISS and both the disease-specific quality of life (DLQI: <math>r = 0.508</math>) and general health (GHQ; <math>r = 0.329</math>).</p>
Trusson et al. 2016 C	[23]	Qualitative study, guideline-based	24 participants	Chemotherapy-induced alopecia	100 %	54 (42–80)	<ul style="list-style-type: none"> <li>- effects of the cancerous disease on the body and interpersonal relationships</li> <li>- statements on hair loss, wigs, and baldness</li> <li>- narrative analysis</li> <li>- sociological approach</li> </ul>	<p>It seems that the visibility of cancer, expressed by the occurrence of hair loss, affects the interpersonal contact.</p>

First author, year of publication, quality*	Reference	Study design	Subjects			Methods and results		
			Number of participants (n)	Type of hair loss	Percentage of female subjects	Mean age in years (range)	Measuring instruments <sup>1</sup>	Relevant results <sup>2</sup>
van Beugen et al. 2016 A	[29]	Quantitative cross-sectional study	150 participants, 50 with hair loss and 47 partners of patients	<ul style="list-style-type: none"> <li>– 54 % alopecia universalis</li> <li>– 18 % alopecia totalis</li> <li>– 26 % alopecia areata</li> <li>– 2 % androgenetic alopecia</li> </ul>	84.0 %	52.2	<ul style="list-style-type: none"> <li>– modified Stroop test (attention bias, internalized stigma)</li> <li>– approach-avoidance tasks (behavioral bias, external stigma)</li> </ul>	Individuals affected by alopecia seem to be preferentially affected by internalized stigma, while patients with psoriasis rather responded to stimuli originating from other persons indicating external stigma.
Schmitt et al. 2012 B	[24]	Qualitative study, guideline-based	20 participants	Chemotherapy-induced alopecia	100 %	53 (34–70)	<ul style="list-style-type: none"> <li>– perceived effects of an accompanying program</li> <li>– effects of hair loss</li> <li>– interpretative phenomenological analysis</li> </ul>	Therapy-accompanying programs supporting women in case of hair loss could help them deal better with the symptoms of hair loss.

Abbr.: N/A, not available.  
<sup>\*</sup>Quality: A > 80 %, B 50–80 %, and C < 50 % of the criteria of the respective guidelines met.  
<sup>1</sup>Measuring instruments that address stigmatization are printed in bold.  
<sup>2</sup>All results related to stigmatization due to hair loss were considered as relevant.  
<sup>3</sup>In this publication, no measuring instrument for detection of stigma was identified.

**Table 4** Measuring instruments used for the quantitative depiction of stigma and their dimensions in relation to stigmatization.

Instrument	Use	External stigmatization	Internalized stigmatization	Not clearly specified*
Hairdex	[25, 27, 28, 30]			X
<i>Feelings of Stigmatization Questionnaire</i>	[26]	X	X	
<i>Internalized Stigma Scale (ISS)</i>	[21]	X	X	
Modified Stroop test	[29]		X	
Approach-avoidance tasks	[29]	X		

\*From the information provided in the literature, it is not possible to conclude whether internalized or external stigmatization is measured.

wearing a wig and was associated with positive statements such as “*I'd had enough sort of that I did get a wig which was great.*” (Female patient, 61 years, England) [23]. In this context, an accompanying program for patients with therapy-induced alopecia was described as a potentially positive addendum for improving quality of life and minimizing internalized stigma [24].

## Discussion

To our knowledge, this systematic review is the first work providing an overview of the evidence of stigmatization in individuals with hair loss. In the available literature, only eleven publications were assessed as relevant for this topic. Irrespective of the cause of hair loss, it is, however, evident that affected individuals frequently suffer from internalized and external stigmatization. With respect to internalized stigma, hair loss is comparable to acne vulgaris and psychiatric diseases, such as depression and anxiety disorders. Internalized stigma is, however, more pronounced than, for example, in vitiligo.

Due to the fact that hair loss may occur as a symptom of several diseases, based on various pathogeneses and with different severity, the identified studies were very heterogeneous [5]. When comparing the studies, it became evident that the reported diminished quality of life due to stigma, as measured by the Hairdex, varied not only between pathologies but also between study populations (alopecia areata: 4.7 [25]; diffuse alopecia: 16.9 to 37.8 [28]; androgenetic alopecia: 5.6 [25] to 20.1 and 26.9, respectively [28]). Based on these findings, patients with diffuse alopecia [28] and women [25] seem to suffer more severely from stigmatization. Furthermore, almost half of the studies addressed hair loss as consequence of an already existing and treated disease, that is, hair loss as side effect. Given that this aspect is important for interpretation of the study results, the corresponding results are discussed separately.

## Measuring instruments

Most studies used the Hairdex developed by Fischer et al. (Table 3) [11]. Given that this is a scale for assessing the quality of life that measures stigmatization only as subscale, these results are difficult to compare with the *Feelings of Stigmatization Questionnaire* [26] or the ISS [21], which are specifically designed to assess stigmatization. While the overall construct of the Hairdex is validated by DLQI and GHQ, it should be taken into account that no comparable scale was used to measure stigmatization when interpreting the subscale for stigmatization. Furthermore, the Hairdex has only been validated in German, though it was also used in other languages. In addition, none of the included publications gave any information on the transformation of the scores for total scale or subscales to the value range of 0–100. The corresponding authors were contacted to clarify this aspect. Three of the four authors responded. One author confirmed transformation of the subscale [28], while two authors reported that they did not make any transformation [25, 27]. This reduces both the informative value and the comparability of the results, thus excluding direct comparison of the studies and adequate individual evaluation of the scores and in consequence immensely diminishing the informative value of this review. Furthermore, the statement “*So far, I have not been taken seriously at all by my physician*” within the stigmatization subscale implies a need of action with respect to recognition of the psychosocial burden by medical personnel. However, exact scores for this question were not reported.

With respect to the stigma-specific questionnaires, it should be noted that the ISS was developed for assessing stigmatization in psychiatric diseases and has not yet been validated in the field of dermatology. Within the present sample, however, it showed plausible scores and good internal consistency, in turn suggesting good reliability [21]. In addition, the *Feelings of Stigmatization Questionnaire* was utilized, a tool that has been used for skin diseases in the

past. While its subscales have been validated for patients with psoriasis and show good consistency [32], they have no proven quality in the two study groups of psychiatric diseases and alopecia. This must be taken into account when interpreting the results. Another measuring instrument was the combination of a modified Stroop test and two approach-avoidance tasks. These instruments are embedded in psychological behavioral research and are well suited to assess stigmatization and its nature – internalized or external – without using a questionnaire [29]. In summary, measuring instruments for both external and internalized stigmatization are covered in the literature. However, these are either not validated or not easily comparable due to the heterogeneity of the studies.

### Hair loss as symptom

Overall, the scores for the subscale of the Hairdex questionnaire [11] vary strongly between both the various pathogeneses and the various study populations. According to these results, patients with diffuse alopecia (16.9–37.8) [28] and women (androgenetic alopecia, women vs. men: 6.4 vs. 4.2;  $p = 0.078$ ) [25] are more severely affected by stigmatization. The comparability of the studies is, however, limited, given that cultural influences, differences in gender distribution, and uncertain methodology regarding the use of the Hairdex may have affected the study outcomes. For example, only in Turkey was more than one of the relevant studies conducted and published. In general, however, the results underscore the psychosocial burden that can be triggered by hair loss [4, 9, 33].

### Therapy-induced hair loss – hair loss as adverse event

Only one study used the Hairdex for the quantitative analysis of therapy-induced hair loss [30]. The corresponding score for stigmatization was comparable with the scores for androgenetic alopecia [27] or slightly visible diffuse alopecia [28]. While the heterogeneity of the populations and the use of a modified and non-validated form of the Hairdex have to be taken into account again, the qualitative studies underscore the findings indicating a high burden due to stigmatization [22–24]. While qualitative studies also often indicate the perceived stigmatization due to stares of others, no quantitative studies on this aspect exist in the literature. Furthermore, there are no quantitative differentiations between tumor classes or strategies of how patients have dealt with stigmatization.

### Limitations and integration into the general context

Possible limitations of this review are the low number of publications, a potential publication bias and the lack of

studies on minors, although it is well-known that hair loss may also occur at this vulnerable age [34]. Furthermore, the quality of the included studies varied strongly, which may have affected the informative value of this review. However, we decided against retrospective exclusion of qualitatively poor studies, given that also these studies have a certain informative value and the available data are already limited. Given that all studies have been evaluated by scientists working in related disciplines and published in peer-reviewed journals with impact factor that are listed in the common medical databases, reliability of the data and an adequate standard may be assumed. Another aspect is the frequent measurement of stigmatization by means of the Hairdex, a questionnaire addressing quality of life [11]. While this is validated as instrument overall and well-accepted based on the frequent use, the informative value of the individual subscales – such as stigmatization – is not guaranteed. Furthermore, methodological information, for example whether the scores for the subscales were transformed into the standardized range from 0–100, is largely missing in the existing literature. If this aspect is viewed in connection with the large differences regarding the scores for the stigmatization subscale between studies (4.7 [25] to 37.8 [28]), it can be assumed that these have no quantitative informative value, either compared with each other or separately. Due to the lacking methodological details, these scores can only be regarded as a trend. Given that this strong limitation applies to four of the eight included quantitative surveys, however, this impairs the generalization of the presented results. Furthermore, these are the only four studies using the same tool for quantification of stigmatization and might, therefore, be useful for quantitative comparison.

In conclusion, individuals with hair loss suffer, irrespective of the specific cause, from internalized and external stigmatization resulting in massive impairment of their quality of life. Despite the resulting high psychological burden for the affected individuals, stigmatization is currently assessed only as one of many factors limiting the quality of life. Specific studies on the topic of stigmatization due to hair loss are rare; longitudinal studies do not exist, although they are strongly recommended. Additionally, methodologically high-quality and reproducible studies are needed that allow comparison between pathogeneses and with other diseases with visible changes are required in order to better assess the stigmatization and the high psychosocial burden caused by hair loss.

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References

- 1 Kanti V, Röwert-Huber J, Vogt A, Blume-Peytavi U. Vernarbende Alopezien. *J Dtsch Dermatol Ges* 2018; 16(4): 435–63.
- 2 Katoulis AC, Christodoulou C, Liakou AI et al. Quality of life and psychosocial impact of scarring and non-scarring alopecia in women. *J Dtsch Dermatol Ges* 2015; 13(2): 137–42.
- 3 Seth D, Cheldize K, Brown D, Freeman EF. Global burden of skin disease: Inequities and innovations. *Curr Dermatol Rep* 2017; 6(3): 204–10.
- 4 Harth W. Psychosomatik der Kopfhaut. *Hautarzt* 2017; 68(6): 445–8.
- 5 Wolff H, Fischer TW, Blume-Peytavi U. The diagnosis and treatment of hair and scalp diseases. *Dtsch Arztebl Int* 2016; 113(21): 377–86.
- 6 Adil A, Godwin M. The effectiveness of treatments for androgenetic alopecia: A systematic review and meta-analysis. *J Am Acad Dermatol* 2017; 77(1): 136–141.e5.
- 7 Blumeyer A, Tosti A, Messenger A et al. Evidence-based (S3) guideline for the treatment of androgenetic alopecia in women and in men. *J Dtsch Dermatol Ges* 2011; 9 (Suppl 6): S1–57.
- 8 Trüeb RM, Dias MFRG. Alopecia areata: a comprehensive review of pathogenesis and management. *Clin Rev Allergy Immunol* 2018; 54(1): 68–87.
- 9 Hunt N, McHale S. The psychological impact of alopecia. *BMJ* 2005; 331(7522): 951–3.
- 10 Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Books, 1963.
- 11 Fischer TW, Schmidt S, Strauss B, Elsner P. Hairdex. *Hautarzt* 2001; 52(3): 219–27.
- 12 Tizek L, Schielein MC, Seifert F et al. Skin diseases are more common than we think: screening results of an unreferral population at the Munich Oktoberfest. *J Eur Acad Dermatol Venereol* 2019; 33(7):1421–8.
- 13 Augustin M, Sommer R, Topp J et al. Umsetzung der WHO Psoriasis-Resolution in die Öffentlichkeit: Ein bundesweites Programm gegen Stigmatisierung bei chronisch sichtbaren Hauterkrankungen. Available from <https://www.egms.de/static/de/meetings/dkvvf2018/18dkvf411.shtml> (Last accessed May 7, 2019).
- 14 Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; 6(7): e1000097.
- 15 Stroup DF, Berlin JA, Morton SC et al. Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis Of Observational Studies in Epidemiology (MOOSE) group. *JAMA* 2000; 283(15): 2008–12.
- 16 National Institute for Health Research (NHS). PROSPERO – International prospective register of systematic reviews. Available from <https://www.crd.york.ac.uk/prospero/> (Last accessed May 7, 2019).
- 17 vonElm E, Altman DG, Egger M et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *J Clin Epidemiol* 2008; 61(4): 344–9.
- 18 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19(6): 349–57.
- 19 Ziehfrend S, Schuster B, Zink A. Primary prevention of keratinocyte carcinoma among outdoor workers, the general population and medical professionals: a systematic review updated for 2019. *J Eur Acad Dermatol Venereol* 2019;33(8): 1477–95.
- 20 Baati I, Mnif L, Masmoudi J et al. Psychological impact of chemotherapy induced alopecia. *Eur Psychiatry* 2010; 25: 869.
- 21 Temel AB, Bozkurt S, Alpsyoy E. Internalized stigma in acne vulgaris, vitiligo and alopecia areata. *J Invest Dermatol* 2017; 137(10): S197.
- 22 Rosman S. Cancer and stigma: experience of patients with chemotherapy-induced alopecia. *Patient Educ Couns* 2004; 52(3): 333–9.
- 23 Trusson D, Pilnick A. The role of hair loss in cancer identity: Perceptions of chemotherapy-induced alopecia among women treated for early-stage breast cancer or ductal carcinoma in situ. *Cancer Nurs* 2017; 40(2): E9–E16.
- 24 Zannini L, Verderame F, Cucchiara G et al. “My wig has been my journey's companion”: perceived effects of an aesthetic care programme for Italian women suffering from chemotherapy-induced alopecia. *Eur J Cancer Care (Engl)* 2012; 21(5): 650–60.
- 25 Gonul M, Cemil BC, Ayvaz HH et al. Comparison of quality of life in patients with androgenetic alopecia and alopecia areata. *An Bras Dermatol* 2018; 93(5): 651–8.
- 26 Kacar SD, Soyucok E, Bagcioglu E et al. The perceived stigma in patients with alopecia and mental disorder: a comparative study. *Int J Trichology* 2016; 8(3): 135–40.
- 27 Sawant N, Chikhalkar S, Mehta V et al. Androgenetic alopecia: quality-of-life and associated lifestyle patterns. *Int J Trichology* 2010; 2(2): 81–5.
- 28 Schmidt S, Fischer TW, Chren MM et al. Strategies of coping and quality of life in women with alopecia. *Br J Dermatol* 2001; 144(5): 1038–43.
- 29 van Beugen S, Maas J, van Laarhoven AIM et al. Implicit stigmatization-related biases in individuals with skin conditions and their significant others. *Health Psychol* 2016; 35(8): 861–5.
- 30 Freites-Martinez A, Shapiro J, Chan D et al. Endocrine therapy-induced alopecia in patients with breast cancer. *JAMA Dermatol* 2018; 154(6): 670–5.
- 31 Tanabe Y, Hayashi K, Ideno Y et al. The Internalized Stigma of Mental Illness (ISMI) scale: validation of the Japanese version. *BMC Psychiatry* 2016; 16.
- 32 Ginsburg IH, Link BG. Feelings of stigmatization in patients with psoriasis. *J Am Acad Dermatol* 1989; 20(1): 53–63.
- 33 Russo PM, Fino E, Mancini C et al. HrQoL in hair loss-affected patients with alopecia areata, androgenetic alopecia and telogen effluvium: the role of personality traits and psychosocial anxiety. *J Eur Acad Dermatol Venereol* 2019; 33(3): 608–11.
- 34 Mandt N, Vogt A, Blume-Peytavi U. Differential diagnosis of hair loss in children. *J Dtsch Dermatol Ges* 2004; 2(6): 399–411.